

# Preface

The President's Cancer Panel is charged under the National Cancer Act of 1971 to monitor the development and implementation of the National Cancer Program and to report promptly to the President on barriers to the Program's effective implementation.

In 1999, following its report on issues of cancer care quality and cancer-related quality of life,<sup>1</sup> the Panel evaluated the evolution and current status of the National Cancer Program as a whole, including its research and delivery components—both public and private—as well as some of the social, economic, and information-related factors that influence its effectiveness. That report to the President described a serious dissonance between the cancer care that research evidence has proven to be effective and the extent to which this care is provided to Americans with cancer and those at risk for the disease.<sup>2</sup>

These findings were the impetus for a series of seven regional meetings conducted by the Panel during 2000 and 2001 to explore in greater detail the barriers that are keeping all Americans from receiving the most appropriate cancer care. Each regional meeting brought together representatives from each of seven to nine states, the District of Columbia, and U.S. Territories (see Appendix A). At the conclusion of the seven meetings, testimony had been received from every state and territory in the nation. Those offering formal testimony included cancer survivors, family caregivers, State health department representatives, local and regional

public and private program administrators, health care providers at all levels, advocates, and volunteers. In addition, all but one meeting included an evening Town Hall to provide additional opportunity for local citizens to raise issues and share personal experiences with the Panel.

In all, 393 individuals provided testimony; of these, 163 were cancer survivors. The Panel appreciates the commitment of so many of the speakers who traveled across great distances, left jobs and family, and endured their own hardship or personal pain to describe the issues of cancer care in America at their most individual levels. The Panel is profoundly grateful to the following individuals who devoted a part of the limited time remaining to them to tell their stories, and who have since died:

- Dante Delledonne
- Karen Kitzmiller
- Ken Giddes
- Sue Kocsis

The following report and recommendations are based on all of the testimony received from June 2000 through May 2001. The Panel recognizes that invited testimony does not carry the weight of empirical study. However, the Panel believes there is a point at which anecdotes become a body of qualitative evidence, and the importance of the issues echoed repeatedly and consistently throughout every part of this country cannot, and must not, be dismissed. These voices of a broken health care system must be heard.